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ABSTRACT

This report presents information on infants and toddlers with disabilities and special health care needs enrolled in Washington State early intervention services. Enrollment numbers, rates, and patterns are discussed. Out of a total of 264,410 children ages 36 months and under, 4,324 were enrolled in an early intervention service plan as of December 1993. Washington State was found to have slightly lower enrollment rates than the national rate. Enrollment was higher among children of Medicaid-eligible families and there were large differences in enrollment rates by ethnicity/race, with higher prevalence and/or reporting of disabilities among American Indians than the nation as a whole. Rural counties were found to have higher enrollment rates than non-rural counties. An examination of risk factors for children under 3 found that low birthweight babies were four and a half times more likely to be enrolled for early intervention services. Appendices provide data and models supporting the report. (CR)

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Birth to Three Early Intervention Study

Enrollment of Washington Children with Disabilities and Special Health Care Needs in Washington State Public Programs

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Birth to Three Early Intervention Study:

Enrollment of Children with Disabilities and Special Health Care Needs in Washington State Public Programs

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Executive Summary

Birth to Three Early Intervention Study: Enrollment of Children with Disabilities and Special Health Care Needs in Washington State Public Programs

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Total Enrolled: 4,324 children under three years of age were found to be enrolled in public early intervention services for disabilities and special health care needs as of December 1, 1993.

Enrollment Versus Estimated Prevalence Rates The rate for children enrolled in these services in Washington (16.4 per 1000) is comparable to the rate found for children with limitations in some daily activity in the National Health Interview Survey (NHIS: 17.5 per 1000).

The above enrollment rate is lower than the planning rate used by the Birth to Six State Planning Project (25.0 per 1000).

Lower Income The enrollment rate is higher among children of Medicaid-eligible families (23.9 per 1000). This higher rate is comparable to the higher prevalence of reported limitations among lower income families surveyed nationally (NHIS: 23.8 per 1000).

Race/Ethnicity There are large differences in enrollment rates by race/ethnicity within the Washington population, even among children of Medicaid Eligible Families.

The general pattern of enrollment by race/ethnicity in Washington conforms to the general pattern of reported limitations found among race/ethnic groups in the national sample (NHIS).

Risk Factors The pattern of enrollment includes a higher enrollment rate for low birthweight babies and for children of substance-abusing mothers than for the general population.

Rural-Urban While there is high variability by Washington counties, rural counties have, on average, higher enrollment rates than do metropolitan and rural-urban counties; among children who are Medicaid-eligible, children in rural counties are far more likely to be enrolled than children in metropolitan and rural-urban counties.

Particular Barriers to Service A qualitative study of barriers to service provides tentative explanations for the above quantitative findings regarding differences in enrollment by rural-urban location, by income level of families, by racial/ethnic groups, and by various risk factors.

The findings on enrollment are based on total statewide counts of enrolled children under three enrolled in service plans on December 1, 1993, from four provider surveys and two agency management information systems matched with Birth Certificate and Medicaid information in the First Steps Database (ORDA, DSHS).

The qualitative findings emerge from one to four hour in-depth, structured, open-ended interviews conducted in April and May 1994 in seven counties with seventy respondents: parents, resources coordinators, private and public service providers.

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*Study funded by **DSHS Birth to Six State Planning Project**, conducted by the Office of Research and Data Analysis, DSHS. Report 7.73, September 1994.*

INTRODUCTION

Study Purposes

This report addresses a number of informational needs of the Birth to Six State Planning Project and of the State Interagency Coordinating Council (SICC) for Infants and Toddlers with Disablilties and Special Health Care Needs and Their Families.

The information gathered and presented here is intended to inform state policy planning and practices regarding enrollment of children in need of Birth to Three Services.

Early Intervention: Purposes, Current Knowledge, Need for Exploratory Information

Based on public law, the preventive and early intervention programs were developed to address this health care issue with the following goals:

- encourage better identification of infants and toddlers with disabilities and special health care needs;
- reach out to draw these children into services;
- require comprehensive and multidisciplinary assessment;
- encourage the development of needed specialized services;
- provide case management services;
- create collaborative inter-agency systems and service plans for these children;
- educate, empower, and support parents;
- educate providers;
- require the creation of inter-agency coordinating councils;

(See Perrin and MacLean, 1988; see also, Gallagher, J.,1989).

Keys to program enhancements were and remain:

- the need to assess who the served and unserved populations are; and
- the need to inventory the completeness of the service delivery system at the local service area level.

Early intervention services have been seen as an important health care enhancement. While some disabilities become apparent only as children pass their third or fourth years (Palfrey, et al., 1987), it was found helpful to refer infants and toddlers for diagnostic and treatment services **as early as possible**.

As with other states, many of the early intervention delivery system epidemiological and service issues remain unclarified in Washington at this time. Peoples-Sheps, et al., 1986, point out a widespread lack of incidence data or prevalence data in this area. In the absence of a universal child health tracking system, Washington is beginning to explore these issues, through combined quantitative and qualitative methods.

Methods

The findings on enrollment are based on total statewide counts of enrolled children under three enrolled in service plans on December 1, 1993 from four provider surveys and two agency management information systems matched with Birth Certificate and Medicaid information in the First Steps Database (ORDA, DSHS).

The qualitative findings emerge from one to four hour in-depth, structured, open-ended interviews conducted April-May 1994 in seven counties among seventy respondents: parents, resources coordinators, private and public service providers.

ENROLLMENT NUMBERS, RATES AND PATTERNS

An Unduplicated Count of Children Enrolled in a Service Plan

The first research task was to determine how many children, less than three years old, were enrolled in at least one disability related service plan provided by three state agencies (i.e., Division of Developmental Disabilities in the Department of Social and Health Services [DDD/DSHS], Department of Health [DOH], Office of the Superintendent of Public Instruction [OSPI],) as of December 1, 1993.

Based on unduplication of names from agency management information systems, provider surveys, and matching information with the First Steps Data Base (maintained by the DSHS Office of Research and Data Analysis), the following total was generated.

- **4,324 children from newborn to 36 months old were "enrolled in a service plan" as of December 1, 1993, out of a total of 264,410 children of the same age living in Washington.**

See Appendix 2 for a detailed description of sources and methods of unduplication.

Cautions

The count of children enrolled in a service plan was limited to all children enrolled as of December 1, 1993. Due to the "snapshot" nature of this count and different definitions of "enrolled" (see below) some children who had received and completed services prior to December 1, 1993 were not counted.

These numbers do not subsume all children under three years of age experiencing disabilities and special health care needs in Washington. They reflect only those children and families needing and found eligible for services provided through DDD/DSHS, DOH and OSPI. They do not include those who may have been potentially eligible for services but, for whatever reason, were not enrolled, nor those who received services through other sources (e.g., private pay, military services, tribal and Indian Health services, migrant services, and so on).

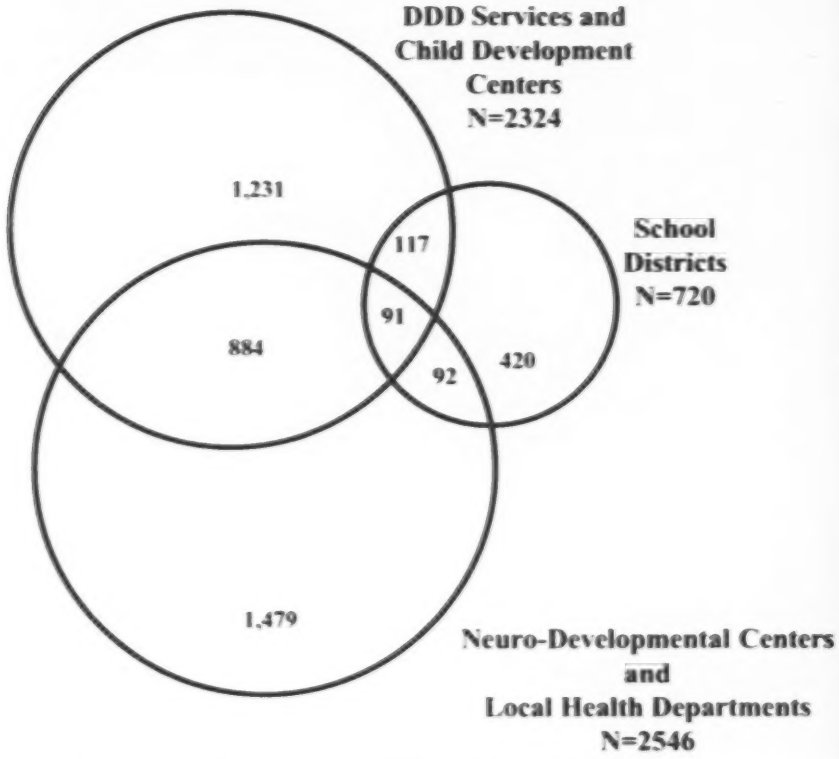
Definitions

"Being enrolled in a service plan" is a convention used to count the number of children who sought and were found eligible for early intervention services funded through the state. Being "enrolled" generally implies that the child has been assessed, determined eligible, and provided with a plan of service, defined somewhat differently by DDD/DSHS, DOH, and OSPI. Because each service area relies on somewhat different eligibility criteria and definitions (e.g., disabling conditions, learning disabilities, medical issues), the definitions used by each service area were incorporated as provided.

Being enrolled does not imply that the child is receiving any or all of the services needed, since children may be awaiting specific diagnoses, approval of eligibility for a particular service, or services from local or non-local providers. A separate report, "The Exploratory Study of Barriers to Birth to Three Services", reports on parents' experiences in obtaining services and professionals' issues in providing services.

Distribution of Enrolled Children by Service Providers

Number of Children Enrolled by One or More Service Providers (overlapping circles indicate more than one provider)



Note: 10 additional children were being served by IFRCs (Interim Family Resource Coordinators) of the Birth to Six State Planning Project: they had a family service plan, but were not yet transitioned into any of the early intervention programs, due, most often, to undetermined eligibility.

This diagram depicts the distribution of 4,324 children under three enrolled in early intervention services by providers of each reporting agency. There is relatively small overlap in the number of children enrolled by more than one agency's providers.

- **Of the enrolled children, 73% were reported to be served by one type of provider only (1,231 + 1,479 + 420 = 3,130), 25% by two types of providers (884 + 117 + 92 = 1093), and 2% (91) by three types of providers.**

Based on the identified overlaps in enrollment, the reporting agencies are examining the causes underlying the overlaps.

Washington State Enrollment Rates and National Prevalence Rates

A second research task was to investigate access to state agency early intervention services by comparing the precise enrollment rates and numbers in the combined state agency programs with estimated rates and numbers of children under three who may need such services. We chose to compare a precise Washington state agency count of enrolled children to one national estimate based on a sample survey of parental reports on their children, which enables us to draw comparisons by race/ethnicity and income.

Our analysis relies on prevalence rates derived from a national probability sample of households -- the National Health Interview Survey (NHIS)*. In the NHIS, parents are asked to identify major or minor **limitations** in daily activity for every person in their household; these **limitations** may only partially correspond to what is defined as **disabilities or special health care needs** in public law and program policies.

Unfortunately, limitation or disability for many infants and toddlers is difficult to estimate. Mild developmental delays in very young children may not be recognized or identified by their parents or caregivers; on the other hand, very severe conditions often result in institutionalization and, thus, removal from the households which are the source of the NHIS information. As a consequence, the resulting rates of reported limitation are considered to be conservative.

In the NHIS, the reported rate of limitations for children under three is 18.3 per thousand; by contrast, the rate for persons under twenty years of age is 40 per thousand. Much of this difference over time is due to later recognition of limitations which have been present since early childhood and to limitations appearing after the children have turned three years of age.

Washington

Washington Children Under Three Enrolled in Early Intervention Programs

All Living in Washington	Children Born to Washington Mothers 1991-1992
16.4 per 1000 4,324/ 264,410	16.1 per 1000 2,596/ 161,043

National Survey

"Parent-Reported" Prevalence Rates for Children Under Three From NHIS 1988 Through 1991

NHIS	NHIS Applied to Washington, Controlling for Poverty Status of Washington Residents
18.3 per 1000 431/ 23,520	17.5 per 1000 4,618/ 264,410

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* *1988-91 NHIS surveys: 200,000 households, about 500,000 persons living in these households, of which 5 percent are less than 3 years old (i.e. about 25,000).*

For research purposes, it is useful to compare the actual enrollment rates and numbers in Washington with NHIS estimates:

- **The 4,324 enrolled children in Washington constitute an enrollment rate of 16.4 per thousand. Of those children born (birth years 1991 and 1992) to mothers who were Washington State residents, the enrollment rate is 16.1 per thousand.** (See table on page 4.) Fully one-quarter of all children enrolled in early intervention services in Washington were born to mothers who were not Washington State residents at the time of the birth of the child; despite this, the two enrollment rates are similar.

- **State enrollment rates are slightly *lower* than the national "parent-reported" prevalence rate of limitations (16.4 per thousand compared to 17.5 per thousand).** The enrollment number of 4,324 children receiving early intervention services is not substantially lower than the 4,618 predicted by applying the NHIS rate to the Washington population.

- **The NHIS-produced national prevalence rate of 17.5 per thousand for children under three with limitations is lower than the 25 per thousand rate used by the Birth to Six State Planning Project.** This is due to expected under-reporting by parents of limitations for their very young children. As the children become older and enter kindergarten, the achieved enrollment rate in Washington is expected to begin to approximate the higher state planning rate.

- **The Birth to Six State Planning Project's rate of 25 per thousand would result in 6,600 children under three in need of services in Washington, compared to the 4,324 enrolled in Washington as of December 1, 1993.** However, it must be noted that the unduplicated count of 4,324 does not include all Washington children receiving services from all other public and private sources. It is also clear that not all Washington children in need of services have been identified, assessed, qualified and enrolled. The Exploratory Study of Barriers in Birth to Three Services identifies some of the reasons for this lack of enrollment among children in need.

The differences in rates noted above reflect the difficulty of identifying, assessing, qualifying, and enrolling all children in need as estimated by experts and planners. However, given that we can calculate enrollment rates and national parental reported rates by race/ethnicity and income, we can draw comparisons among various categories of Washington children and families and between Washington children and families and a national sample.

Distribution of Enrolled Children by Family Income and Ethnicity/Race

The third research task was to identify the composition of enrolled children under three in Washington and the national survey of families with children with limitations by **relative family income** and by **ethnicity/race**.

Family Income Distribution

Washington

% Medicaid-Eligible Among All Children and Enrolled Children Born to Washington Mothers 1991-1992

	All Washington Births N=161,843	B-3 Enrolled Washington Births N=2,584
Medicaid Eligible	37%	61%
Not Medicaid Eligible	63%	39%
	100%	100%

National Survey

% At or Below 185% Federal Poverty Level (FPL) Among All Children Under Three and Those Reported To Have Limitations (NHIS 1988-91)

	All Children Under 3 n=20,341	Children Under Three With Reported Limitations n=374
At or Below 185% FPL	41%	54%
Above 185% FPL	59%	46%
	100%	100%

- **Medicaid-eligible* families are over-represented among enrolled children under three (61% versus 37% born to mothers who were Washington residents at time of birth).**
- **Similarly, families with lower income (below 185% of the Federal Poverty Level [FPL]) are over-represented among children with "parent-reported" limitations nationwide (54% versus 41%).**

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** Medicaid-eligible means that the mother received Medicaid funded maternity care. Medicaid eligibility requirements include being at or below 185% of the FPL.*

Ethnicity/Race Distribution

Washington

Race/Ethnicity of Children Under Three (Born To Washington Mothers 1991-92)

	All Children Washington Born N=161,043	Enrolled Washington Born N=2,584
White (Non-Hispanic)	77.5%	77.5%
Hispanic	8.2%	7.9%
Asian/Pacific Islander	5.2%	2.9%
African American	4.2%	8.4%
American Indian	1.8%	3.9%
Other/Unknown	3.1%	2.4%
	100.0%	100.0%

National Survey

Race/Ethnicity of Children Under Three (NHIS 1988-91)

	All Children Under 3 n=23,510	Children Under 3 With Reported Limitations n=431
White (Non-Hispanic)	60.8%	58.9%
Hispanic	17.1%	14.2%
Asian/Pacific Islander	2.4%	0.7%
African American	17.4%	25.0%
American Indian	0.9%	0.5%
Other/Unknown	13.4%	0.7%
	100%	100.0%

- White children constitute the majority of enrolled children, comparable to their representation in the general population of all Washington born children.
- Children who are identified as White and Hispanic are similarly represented in the Washington enrolled and general populations.
- Asians/Pacific Islanders constitute a smaller proportion among the enrolled than among all Washington born children. American Indians and African Americans constitute a larger proportion among the enrolled than among all Washington born children.
- **The general pattern of enrollment by race/ethnicity for Washington conforms to the national pattern of reported limitations by race/ethnicity, with the exception of American Indians.** This suggests higher prevalence and/or reporting of limitations among American Indians in Washington than in other parts of the nation.

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Enrollment Rates Among Medicaid Eligible

Washington

Washington Enrollment Rates (Born to Washington Mothers 1991-1992)
Medicaid Eligible (<185% FPL) Washington Born Children
23.9 per 1000 N = 57,933

National Survey

National "Parent-Reported" Limitation Prevalence Rates (NHIS 1988-1991) for Children Under Three
At or Less than 185% FPL in the National Sample
23.8 per 1000 n = 8,440

- **The Washington enrollment rate of 23.9 per 1000 is essentially the same as the "parent-reported" prevalence rate of 23.8 per 1000 nationwide, among families with incomes at or below 185% of the Federal Poverty Level.**
- The enrollment rate among Medicaid eligible families in Washington is higher than among all families in Washington: 23.9 per 1000 (see above) compared to 16.1 per 1000 among all families. (See page 4.)

Enrollment Rates Among Race/Ethnic Groups

Washington

Race/Ethnicity of Washington Born Children		
	Enrollment Rate per 1000	**N (Births)**
White (Non-Hispanic)	16.5	37,413
Hispanic	**16.0**	**9,984**
Asian / Pacific Islander	10.3	3,041
African American	**20.9**	**3,777**
American Indian	35.2	2,139

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National Survey

Race/Ethnicity of National Sample		
	Limitations Rate per 1000	n (total sample)
White (Non-Hispanic)	17.8	14,307
Hispanic	**15.1**	**4,033**
Asian / Pacific Islander	n/a	565
African American	**26.4**	**4,092**
American Indian	n/a	207

- **The enrollment pattern by race and ethnicity in Washington is very similar to the "parent-reported" prevalences pattern at the national level.**
- Data from Washington suggest lower enrollment among Asian/Pacific Islanders (10.3/1000 versus 16.5/1000 for Whites), and higher enrollment among American Indians (35.2/1000 versus 20.9/1000 for African Americans and 16.5/1000 for Whites). Without additional data on other variables, no conclusions about under- or over-enrollment can be drawn from these tables.

Enrollment Rates Among Race/Ethnic Groups Who Were Medicaid Eligible

Washington

Race/Ethnicity Among Medicaid Eligible Washington Born Children		
	Enrollment Rate per 1000	N
White (Non-Hispanic)	29.5	2,294
Hispanic	**17.2**	**183**
Asian / Pacific Islander	15.1	549
African American	**28.6**	**232**
American Indian	42.5	61

National Survey

Race/Ethnicity Among Families At or Below 185% FPL in the National Sample of Children Under Three		
	Limitations Rate per 1000	n
White (Non-Hispanic)	24.9	3,651
Hispanic	**20.3**	**1,925**
Asian / Pacific Islander	n/a	184
African American	**27.7**	**2,417**
American Indian	n/a	145

- The enrollment patterns reported above for different race/ethnic groups among all Washington families appear to be the same also among Medicaid eligible families in Washington and among lower income families in the national sample.
- The difference is the generally higher enrollment rates and generally higher reported limitation rates for children of these lower income families.

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County Differences in Enrollment Rates:

The fourth research task was to determine whether Washington counties differ in the degree to which they enroll children under three.

Relying on the First Steps Data Base, we could distribute all children who are **Medicaid-eligible** and all children born in Washington in 1991 and 1992 to the identified county of residence for their mother at the time of the child's birth. In the table, we could then examine the degree to which groupings of counties have enrolled more or fewer children in the total population and, in particular, among Medicaid-eligible families. That is, are families who are Medicaid-eligible enrolled at different rates by county?

County Differences in Proportion of Children Who are Medicaid Eligible

This is an important question since apparent differences in overall enrollment rates by county may be due to different proportions of low income families by county and because families in more rural areas tend to have higher percentages of Medicaid eligible families. Based on the table on the facing page, 53 percent are Medicaid eligible in rural counties, 45 percent in urban/rural ones and only 31 percent in metropolitan ones.

Rural, Rural-Urban and Metropolitan Differences in Enrollment

Referring to the table on the facing page, we found that:

- There is high variability of enrollment rates by county, but rural counties, on average, have higher enrollment rates: 26.1 per 1000 compared to 16.6 per 1000 in rural-urban counties and 14.1 per 1000 in metropolitan counties.
- Among children who were Medicaid-eligible, children in rural counties were far more likely to be enrolled (38.2 per 1000) than rural-urban children (22.5 per 1000) or metropolitan children (24.2 per 1000).
- Some of the variability among rural counties may be attributed to very small numbers, which produce less precise rates; however, the generally higher rate among rural counties suggests better identification and more successful enrollment of children with disabilities in smaller communities.

Variability Among Counties

- The variability among more metropolitan and urban counties may reflect different organization of services as well as different degrees of ruralness in parts of these counties.

Rates of Enrollment by County and County Grouping

		Medicaid-Eligible Washington Born				All Washington Born				
County		Enrolled Children	All Medicaid Children	Rate per 1000	Rate Index: County Over State	Enrolled Children	All Births	Rate per 1000	Rate Index: County Over State	Index Ratio (Med/All)
Clark	m	50	2416	20.7	0.80	93	6780	13.7	0.85	0.93
King	m	340	12874	26.2	1.01	629	46962	13.4	0.83	1.21
Pierce	m	133	7316	18.2	0.70	259	21040	12.3	0.77	0.91
Snohomish	m	142	4497	31.6	1.22	292	16427	17.8	1.11	1.10
Spokane	m	108	4733	22.8	0.88	173	11302	15.3	0.95	0.92
Metropolitan Total		773	31936	24.2	0.93	1446	102511	14.1	0.88	1.06
Benton	u/r	37	1686	21.9	0.85	63	3970	15.9	0.99	0.86
Cowlitz	u/r	34	1216	28.0	1.08	44	2566	17.1	1.07	1.01
Franklin	u/r	24	1309	18.3	0.71	35	1957	17.9	1.11	0.63
Kitsap	u/r	32	1463	21.9	0.84	108	7181	15.0	0.94	0.90
Lewis	u/r	34	937	36.3	1.40	52	1760	29.5	1.84	0.76
Skagit	u/r	16	1205	13.3	0.51	20	2864	7.5	0.47	1.09
Thurston	u/r	45	1728	26.0	1.00	84	4989	16.8	1.05	0.96
Walla Walla	u/r	28	845	33.1	1.28	32	1457	22.0	1.37	0.93
Whatcom	u/r	28	1450	19.3	0.74	61	3893	15.7	0.98	0.76
Yakima	u/r	125	6069	20.6	0.80	148	8615	17.2	1.07	0.74
Rural-Urban Total		403	17666	22.5	0.87	647	38052	16.6	1.03	0.84
Adams	r	5	443	11.3	0.43	7	595	11.8	0.73	0.59
Asotin	r	11	241	45.6	1.76	14	398	35.2	2.19	0.80
Chelan	r	35	1222	28.6	1.10	44	1966	22.4	1.39	0.79
Clallam	r	29	724	40.1	1.54	40	1453	27.5	1.71	0.90
Columbia	r	4	60	66.7	2.57	5	100	50.0	3.11	0.83
Douglas	r	8	493	16.2	0.63	13	827	15.7	0.98	0.64
Ferry	r	3	113	26.5	1.02	3	184	16.3	1.02	1.01
Garfield	r	0	16	0.0	0.00	0	36	0.0	0.00	0.00
Grant	r	37	1479	25.0	0.96	45	2276	19.8	1.23	0.78
Grays Harbor	r	113	1210	93.4	3.60	125	1969	63.5	3.95	0.91
Island	r	14	350	40.0	1.54	36	2169	16.6	1.03	1.49
Jefferson	r	13	256	50.8	1.96	15	477	31.4	1.96	1.00
Kittitas	r	8	327	24.5	0.94	10	657	15.2	0.95	0.99
Klickitat	r	5	276	18.1	0.70	6	419	14.3	0.89	0.78
Lincoln	r	3	68	44.1	1.70	5	183	27.3	1.70	1.00
Mason	r	15	493	30.4	1.17	18	1023	17.6	1.10	1.07
Okanogan	r	35	830	42.2	1.63	40	1117	35.8	2.23	0.73
Pacific	r	10	213	46.9	1.81	13	350	37.1	2.31	0.78
Pend Oreille	r	4	180	22.2	0.86	6	265	22.6	1.41	0.61
San Juan	r	2	90	22.2	0.86	3	231	13.0	0.81	1.06
Skamania	r	4	92	43.5	1.68	6	173	34.7	2.16	0.78
Stevens	r	18	524	34.4	1.32	20	836	23.9	1.49	0.89
Wahkiakum	r	1	26	38.5	1.48	2	65	30.8	1.92	0.77
Whitman	r	6	295	20.3	0.78	9	800	11.3	0.70	1.12
Rural Total		368	10021	36.2	1.47	485	18589	26.1	1.63	0.91
Total *		1565	60312	25.9	1.00	2586	161043	16.1	1.00	1.00

Rural-Urban Classification by county using criteria developed by Human Resource Profile codes, Economic Development Division of Economic Research Service, USDA.

** The state total includes those children whose county residence could not be determined.*

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ELEMENTS OF RISK FOR CHILDREN UNDER THREE

Shifting focus away from demographics such as race/ethnicity, income, and geography, the available First Steps data allowed us to examine risk factors, such as Low Birth Weight and Maternal Substance Abuse. These are risk factors addressed by state service programs .

Low Birthweight

Weight Group Distribution	Enrolled Children Under Three N	%	Washington State Births 1991 - 1992 N	%	Enrollment Rate per 1000
Very Low Birthweight (<3.3 lbs)	167	6.5%	966	0.6%	172.9
Medium Low Birthweight (3.3 - 5.5 lbs)	321	12.4%	5,637	3.5%	56.9
Normal Birthweight	1,940	75.0%	150,736	93.6%	12.9
Multiple Gestation (Twins, etc.)	134	5.2%	3,543	2.2%	37.8
Missing	24	0.9%	161	0.1%	
Total	2,586	100.0%	161,043	100.0%	

- The percentage of overall low birthweight among children enrolled in early intervention services (18.9%) is **four and a half times** that for statewide births (4.1%). The percentage of very low birthweight among enrolled children is almost **eleven times** that for statewide births: 6.5% versus 0.6%.
- The rate of enrollment increases as birthweight decreases: from 12.9 per 1000 for normal birthweight to 172.9 per 1000 for very low birthweight.

Substance Abuse

Diagnosed Maternal Substance Abuse	Enrolled Children Under Three N	%	Washington State Births 1991 - 1992 N	%	Enrollment Rate per 1000
Alcohol	37	2.4%	664	1.1%	55.7
Both	63	4.0%	784	1.3%	80.3
Drug	123	7.9%	2,171	3.6%	56.7
Neither	1,342	85.8%	56,693	94.0%	23.7
Total	1,565	100.1%	60,312	100.0%	

NOTE: Substance abuse diagnoses are available only for Medicaid cases

Among the Medicaid eligibles:

- The percentage of maternal substance abuse for children under three enrolled in early intervention services (2.4 + 4.0 + 7.9% = 14.3%) **is two and a half times** that for statewide births (1.1 + 1.3 + 3.6 = 6%).
- The rate of enrollment is highest for children of mothers who are diagnosed as abusing both alcohol and drugs: 80.3 per 1000. Alcohol or drug use is associated with similar enrollment rates for their children: 55.7 and 56.7 per 1000 respectively.

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Substance Abuse Within Race/Ethnic Groups

WITH DIAGNOSED MATERNAL SUBSTANCE ABUSE			
Race/Ethnic Groups	**Enrolled Children Under Three**	**All Medicaid Births**	**Rate per 1000**
White (Non-Hispanic)	117	2,294	51.0
Hispanic	**5**	**183**	**27.3**
African American	34	549	61.9
American Indian	**17**	**232**	**73.3**
Asian/Pacific Islander	3	61	49.2
Other/Unknown	**8**	**158**	**50.6**
Total	**184**	**3,477**	**52.9**

WITHOUT DIAGNOSED MATERNAL SUBSTANCE ABUSE			
Race/Ethnic Groups	**Enrolled Children Under Three**	**All Medicaid Births**	**Rate per 1000**
White (Non-Hispanic)	988	35,119	28.1
Hispanic	**167**	**9,801**	**17.0**
African American	74	3,228	22.9
American Indian	**74**	**1,907**	**38.8**
Asian/Pacific Islander	43	2,980	14.4
Other/Unknown	**35**	**3,800**	**9.2**
Total	**1,381**	**56,835**	**24.3**

- Overall, the enrollment rate of 52.9 per thousand among children of higher-risk Medicaid-eligible, diagnosed substance-abusing mothers is **more than twice** the 24.3 rate for children of other Medicaid mothers without such diagnosed problems. (See totals in above tables.)

- The observed enrollment rates appear to be higher for children of diagnosed substance-abusing mothers within all ethnic groups.*

Other Elements of Risk

Low birthweight and history of maternal substance abuse are just two of a number of risk factors which occur with greater frequency among enrolled Birth to Three clients than in the general population of children under three in Washington. Such characteristics may be used as markers for populations at risk and are not necessarily the direct cause of enrollment. Further study has demonstrated additional risk factors associated with enrollment: infant's Apgar score at birth, infant's gender, infant's gestational age and the mother's age compared to the number of previous children. The other elements of risk which are statistically significant are: inadequate prenatal care, smoking during pregnancy, mother's marital status, mother's race/ethnicity and mother's Medicaid eligibility. These are described in more detail in Appendix 3, Table 2.

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* *Statistically, enrollment rates are higher for white, African American, and American Indian children. Among Hispanic and Asian/Pacific Islander children, the small numbers do not allow us to state the statistical significance of the observed differences in enrollment rates between children of substance abusing and not substance abusing mothers.*

Enrollment Rate by Condition and Average First Year Medicaid Expenditures

Enrollment Rates by Congenital and Acquired Conditions

Of further interest, particularly to medical providers, is the extent to which enrollment rates vary by congenital and acquired conditions diagnosed in the first year of life. This additional research task was made possible by available medical diagnosis data for Medicaid children in the First Steps Database.

- **The table on the following page suggests that enrollment for early intervention services is somewhat more independent of some early medical diagnoses than of others. Down's Syndrome, with high correspondence between diagnosis and service, appears to be a model condition for enrollment in early intervention services:**
  - it is highly visible at birth;
  - physicians will tend not to miss the signs of the condition;
  - physicians will tend to attach the same diagnosis to the condition;
  - the condition is commonly the target of multidisciplinary interventions (medical, social, developmental); and
  - providers generally agree that early intervention can be effective in treating the condition and its impact on the child's life.

Other conditions may fail to meet one or more of these criteria for a variety of reasons. Often, these conditions

- can be and are resolved following diagnosis;
- do not appear to providers to be priority targets for early intervention;
- are perceived (correctly or incorrectly) by parents and/or physicians to be unrelated or distantly related to developmental delays;
- may vary in severity of presentation, so that any particular child may not need early intervention services; and
- are specific to children with no other diagnosed conditions.

It can be concluded that

- many medical conditions do not correspond directly to the definitions and criteria of delaying and disabling conditions within each major early intervention service area;
- parents of children with these conditions may not perceive their children to be in need of services and, thus, not seek the services;
- many of these conditions are mediated by individual evaluation, by both parents and physicians.

First Year Medical Costs for Enrolled Children by Specific Conditions

- **The first year Medicaid costs for Birth to Three enrolled children with most of these conditions are high: on average $22,176, excluding disorders not found.** Parents and providers suggest that these reflect only a portion of the costs for this year and the ensuing two years; indeed, Medicaid itself generally reimburses at approximately 60% of billed costs. The balance of all costs may be met through private pay, private insurance, alternative payers (e.g., military, Indian Health Service, tribal health service), charitable grants, and hospital and physician deferral, forgiveness, or non-recoverable write-offs. Parents and providers suggest that true medical and other costs are many times these Medicaid figures.

Birth To Three Enrollment Rate and Average First Year Medical Expenditures for Medicaid Children with Congenital and Acquired Medical Conditions

	All Diagnosed First Year Only	Enrolled B-3 Up to 3 Years of Age	Enrolled in B-3 as % of Diagnosed	Enrolled B-3 Mean First Year Medicaid Expenditure*
Down's Syndrome	55	50	90.9%	$23,032
Cleft Lip/Palate	81	47	58.0%	$15,251
Other Congenital & Chromosomal Anomalies	279	65	23.3%	$29,778
Congenital Musculoskeletal Deformities and Congenital Anomalies of Limbs	2,196	179	8.2%	$25,584
Cerebral Palsy	67	31	46.3%	$45,800
Neoplasms, Diseases & Congenital Anomalies of the Nervous System	8,117	380	4.7%	$22,537
Congenital Anomalies of Heart & Circulatory System	671	78	11.6%	$33,334
Endocrine, Nutritional & Metabolic Diseases & Immunity Disorders	1,380	62	4.5%	$10,152
Coagulation Defects	10	0	0.0%	
Certain Conditions Originating in the Perinatal Period	2,752	115	4.2%	$13,685
Hearing Loss, Congenital Anomalies of Ear, Face, and Neck	154	11	7.1%	$5,442
Mental Retardation	0	0	0.0%	
Developmental Speech & Language Disorder	9	1	11.1%	$20,077
Hyperkinetic Syndrome of Childhood	10	1	10.0%	$4,902
Other Mental Disorders	170	8	4.7%	$3,972
Other Developmental Disorder or Delay	78	27	34.6%	$4,024
Specific Learning Disorders	0	0	0.0%	
TOTAL	16,029	1,055	6.6%	$22,176
Disorder not Found, Benign Murmur	8,770	171	n/a	$3,717

Medical diagnoses from Medicaid claims for the infants' first year of life (from the First Steps Database) were reviewed and categorized based on expected age of appearance of the disorder. The categorization of ICD-9 codes was developed by Laurie Cawthon, M.D., M.P.H. for the Child Development and Rehabilitation Center in Portland, Oregon. Similar methods were described by Palfrey, et. al. (1987) and these principles were discussed more recently in an article by First and Palfrey (1994). See Appendix 4 for a favorable comparison of ascertainment rates of major birth defects for Medicaid children in Washington with national and regional rates reported for all children by the Centers for Disease Control (CDC).

* *This does not include private pay, non-Medicaid public expenditures, or non-reimbursed physician/hospital costs.*

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Qualitative Findings Related to Enrollment Patterns

Exploratory Study of Barriers to Service

The Birth to Three Early Intervention Study includes an exploratory study of barriers to services in seven Washington counties. The findings appear in a separate report published in September 1994. However, they also reflect on the preceding quantitative findings.

Methods of Exploratory Study

Approximately 70 in-depth structured, open-ended interviews were conducted with

- parents of infants and toddlers with disabilities or special health care needs;
- interim family resource coordinators;
- Parent-to-Parent liaisons;
- parent advocates;
- community and cultural organizations; and
- state agency, school, and private providers.

These candid, detailed, and sometimes emotional interviews ranged between one and four hours each to complete. The interviewees were identified through a "snowball" sampling technique, in which initial interviewees directed or introduced us to other interviewees, with the purpose of providing a wide range of perspectives on family needs and local early intervention services. While a broad sample of local provider agency informants was interviewed, the parents we interviewed were largely, but not limited to the parents of children with significant disabilities, that is, those who have the greatest need for the widest array of services.

These parents described, in detail, the common features and barriers throughout the early intervention services system. They were not able to relay to us the experiences of

- parents of children with less severe or short-term conditions;
- parents who had alternatives to these public services; or
- parents of children who, for one reason or another, have not received services.

The exploratory analytic method we used is found in Glaser and Strauss, The Discovery of Grounded Theory (Aldine, 1967). In this method, data analysis occurs concurrently with data collection; discovered field data drives the analysis and analysis identifies new field data collection avenues. Grounded theory assumes that, in the absence of specific theory or hypotheses, explanatory theory should be derived from systematic observations of real life.

Race/Ethnicity and Enrollment in Service

Respondents suggest that the relationship between race/ethnicity and the rate of being in early intervention public services is explained by cultural, socioeconomic, and service factors. They suggest that different rates of utilization reflect the following:

- different cultural ways of perceiving and valuing disabilities and special health care needs,
- significant language differences;
- different willingness to tolerate outside assistance in family life sometimes viewed as intrusion;
- different levels and types of immediate social support for the family;
- different rates of substance abuse and other risk factors;
- degree of urbanization; and
- different service frameworks based on race/ethnicity such as the Indian Health Service and Migrant Services.

Poverty and Enrollment in Service

The rate of enrollment into early intervention services appears more markedly related to increasing poverty, and less markedly related to race/ethnicity. Respondents reported that having a child with one or more serious disabilities results quite often in marked and very rapid decline in family economic status, increasing the likelihood of Medicaid-eligibility. This decline threatens family stability but makes the child eligible for a greater array of public services:

- Some families take deliberate steps to move farther down the income ladder in order to qualify their children or themselves for services.
- Families experiencing economic stress also include single parent families, families with other members experiencing disabilities or special health care needs, and families at geographic distance from extended family and friends.

In and Out-migration: All Families and Military Families

Approximately 25% of all children enrolled in early intervention services in Washington were born to mothers who were not Washington residents at the time of the child's birth. The parents of these children either migrated to Washington or the children were adopted by Washington families. While in-migration to Washington occurs for many reasons, respondents suggest that the migration of children with disabilities or special health care needs may be disproportionately represented, due to

- the intention by some families to enter a state with a greater reported array of services and
- the national flow of military families containing an "exceptional family member" to military medical facilities in Washington, especially in one county where the major medical facility for this region of the country is housed.

Among immigrants, the degree of disproportionality of children with disabilities or special health care needs, if any, is unknown.

Some parents suggest that they remain in Washington, although they have family and other resources elsewhere, due to their attachment to the local early intervention service network which supports them.

Urban vs. Rural Enrollment Rates

Service enrollment of children among Medicaid-eligible families appears to increase considerably as one moves from more urban to more rural counties, even though there is a greater concentration and array of services in the urban areas. Being resource-rich may not result in greater, but lesser, utilization rates, due to higher agency caseloads, more inter-system coordination problems, and more families leaving service in the absence of agency retention efforts. Respondents suggest that children with a disability or special health care need are more likely to be identified and provided with coordinated assessment, planning, referral, and family support services in more rural counties, due to their higher visibility among smaller populations and less complex service systems. Although they may have access to far less complete and specialized services and somewhat less quantity of service (in some specialty services), they do not tend to fall "between the cracks" as may happen to their more urban counterparts.

Maternal Substance Abuse and Family Empowerment

The presence of maternal substance abuse is reported to be a significant factor not only in the likelihood of a disability or special health care need among children but in the subsequent provision of services to mothers and children. For example, one mission of Interim Family Resource Coordinators is to assist families to take control and to effectively claim certain public services. These coordinators report great difficulty in empowering families weakened by dependency on substances. Equally, service providers suggest that such families have greater difficulty following through on planned actions for their children.

Characteristics of "Gates" to Service and Enrollment

Recent reports by and discussions with involved state agency personnel and community-based advocates provided a wealth of information, suggesting in particular the existence of a number of formidable "gates" to service, any one of which could pose a barrier to service. Our preliminary conclusion supports and extends the information about "gates" and their attributes; parents, in particular, described the efforts they have had to expend in order to pass through gates which are not designed to stop them but, in practice, do stop or delay access to services.

Parental Concerns Related to Obtaining Services

The interviewees extended the topics of concern well beyond those defined by the focused early intervention services issues alone; they encompassed almost every element related to

- developmental special health care needs;
- medical needs;
- family support needs;
- the concomitants of poverty;
- local inter-agency coordination;
- the relationship between military and civilian services;
- the role of private providers and clinics;
- shortages of providers;
- housing and respite needs; and
- health care reform alternatives.

The findings of this exploratory study appear in a separate report entitled, "Exploratory Study of Barriers to Birth to Three Services: Children with Disabilities in Washington State Public Programs" (Report #7.78).

Appendices

APPENDIX 1

Table 1

The Expected Number of Children with Activity Limitations, Based on National "Parent-Reported" Prevalence Rates, Applied to Estimated 1993 Washington Population

County	[1] Total Age 0-2	[2] Age 0-2 Below 100% Poverty	[2] Age 0-2 Between 100% - 185% Poverty	[2] Age 0-2 Above 185% Poverty	[3] Age 0-2 with Activity Limitation
Adams	879	273	334	272	18
Asotin	872	399	98	375	20
Benton	6,898	1,212	1,358	4,328	122
Chelan	2,920	684	756	1,480	55
Clallam	2,720	608	683	1,429	50
Clark	14,286	2,057	2,769	9,460	244
Columbia	164	48	43	73	3
Cowlitz	4,159	1,055	745	2,359	79
Douglas	1,502	319	309	874	27
Ferry	371	141	34	196	8
Franklin	2,629	956	581	1,092	55
Garfield	83	13	20	50	1
Grant	3,674	1,070	1,050	1,554	72
Grays Harbor	3,234	891	716	1,627	63
Island	3,704	443	1,229	2,032	62
Jefferson	929	186	246	497	17
King	72,036	7,634	8,323	56,079	1,181
Kitsap	11,640	1,825	2,573	7,242	201
Kittitas	1,095	186	293	616	19
Klickitat	881	234	266	381	17
Lewis	3,037	715	775	1,547	57
Lincoln	385	73	122	190	7
Mason	1,956	411	425	1,120	36
Okanogan	1,808	589	535	682	37
Pacific	837	279	174	384	17
Pend Oreille	491	175	121	195	10
Pierce	35,761	6,382	7,705	21,674	633
San Juan	498	42	111	345	8
Skagit	4,326	751	878	2,697	76
Skamania	468	84	110	292	8
Snohomish	29,136	2,723	3,950	22,463	471
Spokane	18,842	3,781	4,243	10,818	341
Stevens	1,695	498	434	763	33
Thurston	8,882	1,466	1,725	5,691	155
Wahkiakum	118	21	27	70	2
Walla Walla	2,369	568	400	1,401	44
Whatcom	6,592	1,050	1,368	4,174	114
Whitman	1,298	234	269	795	23
Yakima	11,239	3,886	2,597	4,756	232
State Total	264,410	43,942	48,395	172,073	4,618

This table provides county estimates of expected numbers of rates among children in need of services. These numbers, while potentially useful, must be read with caution, due to the uncertain accuracy of the estimated Washington census figures by county and the uncertain validity of equating "parent-report of activity limitation" with children experiencing disabilities or special health care needs as defined in federal and state law.

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Footnotes for table on facing page:

1. These figures for children, under three years of age, are derived from a 1993 Office of Financial Management (OFM) estimated total of Washington children, 0-4 years of age, for all counties. This total was reduced by subtracting those children older than 36 months, leaving a statewide total of 264,410, disaggregated by county.

2. The 1990 Washington census provided poverty rates for each county. These rates were applied to the 1993 OFM estimated population of children, under three years of age, by each county. This produced numbers of children in each county living below 100% of the federal poverty level (FPL), between 100-185% of the FPL, and above 185% of the FPL.

3. The rates for "parent-reported" activity limitation appearing in the National Health Information Survey were applied to each county based on the family income characteristics appearing in columns 2-4. This generated an expected number of children, by county and statewide, experiencing an activity limitation. This number cannot be compared directly to the actual number of children enrolled in an early intervention service for each county and statewide, because the Washington table calculates only two years of births to Washington state mothers whereas this table is an estimate of all children under three in the Washington population.

Table 2
Age and Gender Distribution Among Children Enrolled in Early Intervention Services in Washington

Age Distribution		
0 - 6 months	338	7.8%
7-12 months	568	13.1%
13-18 months	758	17.5%
19-24 months	748	17.3%
25-30 months	918	21.2%
31-36 months	994	23.0%
Total	4324	
Average Age	21.6 months	

Gender Distribution		
Female	1800	41.6%
Male	2520	58.4%

The proportion of boys (58.4%) among enrolled children in Washington is similar to the higher proportion of boys among children with limitations nationally (NHIS 1988-91): 60% among children under 17.

APPENDIX 2

The Unduplication Process and Schematic

Timing

The task of unduplicating individuals with identifiers from four survey sources, two Management Information Services (MIS) sources, and First Steps Database began when the preliminary disks from the Developmental Disabilities Division of DSHS (DDD), and DOH's MIS were received January 19, 1994. Methods for input, standardization of variables, and preliminary programs for name scanning were completed by January 26, 1994. The survey source information was delivered February 17, 1994. It was then decided that the entire last name would be requested from DDD for clients in their MIS. This was delivered on February 18, 1994. The DOH MIS information was delivered February 24, 1994. The format varied from the first disk and adjustments to input procedures had to be made. Step 5 was reached on February 28, 1994. The match and verification process was completed on March 14, 1994 and analysis began.

Sources and General Matching Procedures

A chart is attached which contains the numbers of records in each original source, the sources which were compared, the number of unduplicated records which were the outcome of that comparison, the dataset names of information at various steps, and the final outcome counts and dataset names.

In addition to the client's name, the date of birth (dob) for each client and his/her gender were crucial in matching. That information was standardized in each data source before matching records from other sources. A printout of the actual listing and decisions made is available.

Twins and possible twins were flagged during matching and unduplicated by hand at the end of matching, since they represent a large percentage of the population and an additional hazard in the matching process. It is much more likely that twins share the same first and middle initial and they usually share the same dob. By the end of the process it was much easier to distribute the records correctly between twins.

After matching to First Steps Database (FSDB) there was additional information on those matched. The additional middle names, and maiden, legal and child's last names allowed some records to be consolidated which had been regarded as two or even three children. This process emphasizes the importance of matching to the FSDB in order to further unduplicate the personal identification codes (pics).

Detailed Steps for Unduplication

The following steps describe this process in greater detail; the step numbers are indicated on the process diagram which follows (see page 25):

1) Unduplicate by pic each of the survey sources against itself, finding multiple reporting of individuals.

   a) Some clients (42) were missing their gender; these were searched for in all sources and the gender found for 18. Of the twelve remaining, nine were found in the updated DOH MIS, leaving only three with no gender. These three had no records that matched to them in any of the sources including FSDB. A printout of these records and the decision made is available.

b) One client was missing the day portion of the date of birth, but a multiple record was found in another source and the date completed before matching to other sources.

2) Unduplicate by pic the surveys from Birth to Six, DDD, OSPI, and DOH finding multiple sources. This resulted in one pool of pics for all survey records. Almost twenty-two percent of the records were duplicates.

3) Unduplicate DOH MIS against itself by name, gender, and dob to find multiple reporting of individuals.

a) Date of birth, icd-9 codes and race were standardized to conform to FSDB codes before the information was matched.

b) The name field was combined into one variable by several different methods. The field was scanned and divided into last names, first names and middle names. Almost 200 had quoted additional information, such as deceased, jr., an additional name option, or delete. These were hand edited into their name options.

4) Unduplicate DDD MIS against itself by name, gender, and dob to find multiple reporting of individuals.

a) One client record was missing the dob, but the client was listed in another source with dob. The information was completed before matching was done.

5) Unduplicate DOH and DDD MIS systems against each other, providing a pool of MMIS names and an indicator of sources.

6) Unduplicate the name pool (5) with the survey pool (2) above by pic to attach names, and allow access to other demographic data, for example, race/ethnicity.

a) Although race had been standardized to match with FSDB data, it was not available on enough records to be truly useful.

7) For those records with names, present in (5), match against First Steps Database to allow access to birth and Medicaid records for additional demographic or diagnostic data.

8) For those records without names, not present in (5), match against First Steps Database using pic, and more relaxed criteria.

a) Printed out a pseudo-random 100 records which matched at this level for both their source information and FSDB link file information. A colleague reviewed those for correctness. No incorrect matches were identified.

b) Printed out the unmatched source records for 93 births. These were checked for sound-alike names, misspelled names, incorrect dob and other common errors that prevented them being matched or collapsed correctly.

c) Verified the tentative matches and changes, then made the definite changes and matches.

d) Printed out the twins and unscrambled their records; also collapsed records of those who were not twins, but appeared to be due to a middle initial discrepancy or some other error.

e) Verified any records that matched to more than one FSDB client. If a correct choice was not clearly evident, the match options were discarded, and no match was made.

9) Provide a file of unduplicated clients, which sources they appear in, and their respective ids in those sources. Normalized that information and created a universal id (groupid) that is linked to all records in all sources for a single client.

Suggestions for Future File Identification

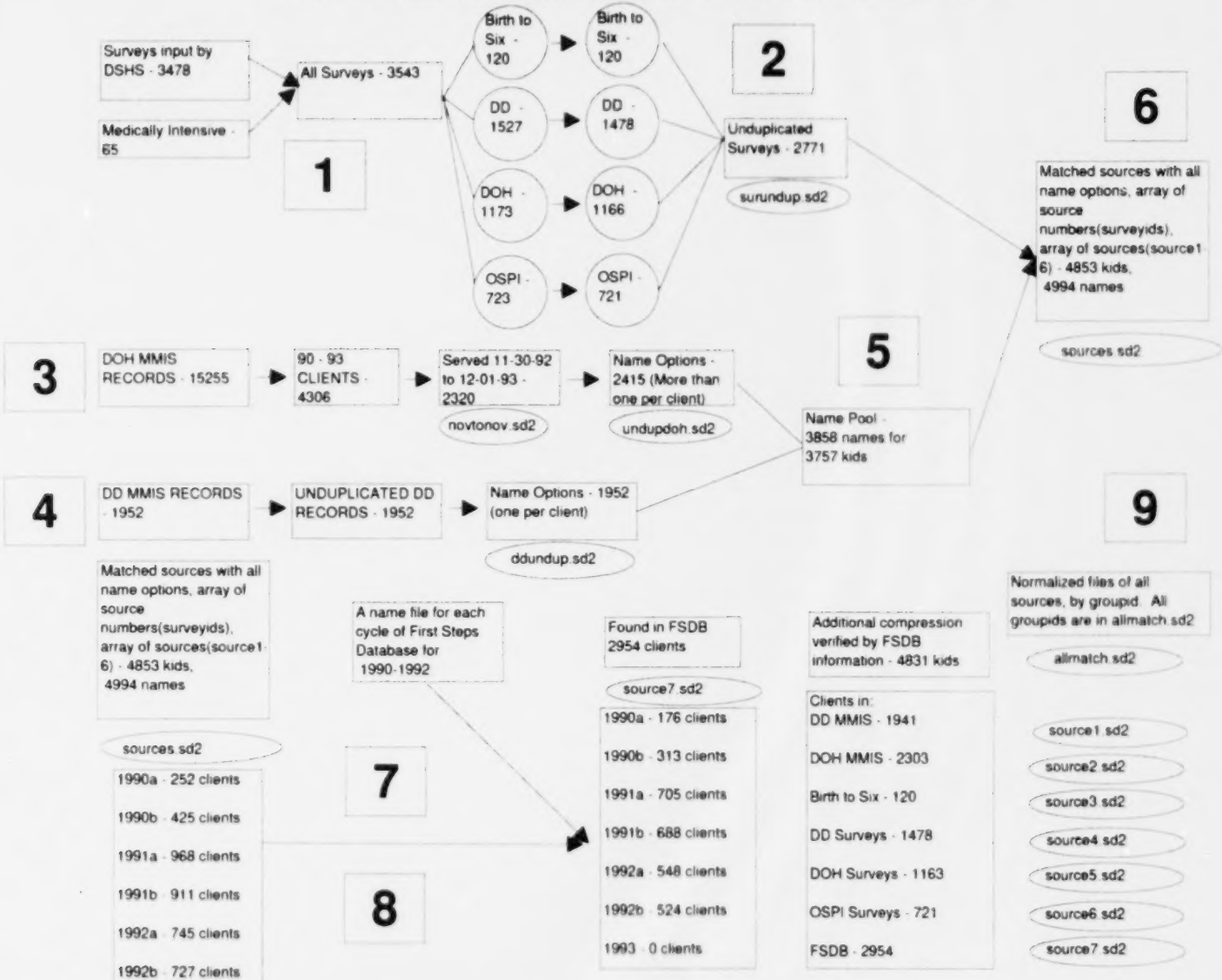
There should be a separate file with a key identifier for each additional non-unique data item. For example, a file with a record for each name option and a key identifier, a file with a record for each source identifier and a key identifier, a file with a record for each child and an identifier.

Consolidation without losing or overwriting data is simplified a great deal by this method. While it increases the merge time necessary to create some information, the time saved for alterations or updates far exceeds that time allotment. This method requires the creation of a group id for all sources, but that group id can be a linking factor in analysis of data from all input data sources.

Suggestions for Future Matching

Pic code information on a client is **not** enough for matching. For a comprehensive match full names are needed, with alternate names if available. It is desirable to have race/ethnicity, address, ssn, place of birth or some other tie-breaking data element. That data element should be consistently available across the client pool. While additional information was available for this match it was at best only available for some clients. This increases the handmatching necessary.

PROCESS DIAGRAM OF
BIRTH TO THREE UNDUPLICATION AND MATCH TO FIRST STEPS DATABASE


Surveys input by DSHS - 3478
Medically Intensive - 65
All Surveys - 3543
1
Birth to Six - 120
DD - 1527
DOH - 1173
OSPI - 723
Birth to Six - 120
DD - 1478
DOH - 1166
OSPI - 721
2
Unduplicated Surveys - 2771
surundup.sd2
6
Matched sources with all name options, array of source numbers(surveyids), array of sources(source1 6) - 4853 kids, 4994 names
sources.sd2
3
DOH MMIS RECORDS - 15255
90 - 93 CLIENTS - 4306
Served 11-30-92 to 12-01-93 - 2320
novtonov.sd2
Name Options - 2415 (More than one per client)
undupdoh.sd2
5
Name Pool - 3858 names for 3757 kids
4
DD MMIS RECORDS - 1952
UNDUPLICATED DD RECORDS - 1952
Name Options - 1952 (one per client)
ddundup.sd2
9
Matched sources with all name options, array of source numbers(surveyids), array of sources(source1 6) - 4853 kids, 4994 names
sources.sd2
A name file for each cycle of First Steps Database for 1990-1992
7
8
1990a - 252 clients
1990b - 425 clients
1991a - 968 clients
1991b - 911 clients
1992a - 745 clients
1992b - 727 clients
(no FSDB records 1993 - 803 clients
Found in FSDB 2954 clients
source7.sd2
1990a - 176 clients
1990b - 313 clients
1991a - 705 clients
1991b - 688 clients
1992a - 548 clients
1992b - 524 clients
1993 - 0 clients
Additional compression verified by FSDB information - 4831 kids
Clients in:
DD MMIS - 1941
DOH MMIS - 2303
Birth to Six - 120
DD Surveys - 1478
DOH Surveys - 1163
OSPI Surveys - 721
FSDB - 2954
Normalized files of all sources, by groupid. All groupids are in allmatch.sd2
allmatch.sd2
source1.sd2
source2.sd2
source3.sd2
source4.sd2
source5.sd2
source6.sd2
source7.sd2

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Match Rate for Birth to Three Clients File Against All Children Born to Washington State Mothers (First Steps Data Base January 1990 - December 1993)

Frequency Percent Row Pct Col Pct	No	Yes	Total
1990 Jan - June	76 30.16	176 69.84	252 100%
1990 July-Dec	112 26.35	313 73.65	425 100%
1991 Jan - June	263 27.17	705 72.83	968 100%
1991 July - Dec	223 24.48	688 75.52	911 100%
1992 Jan - June	197 26.44	548 73.56	745 100%
1992 July - Dec	203 27.92	524 72.08	727 100%
1993 Jan - Dec	803 42.78	0 0.00	803 100%
Total (without 1993 data)	1074 26.66	2954 73.34	4028 100%

The match rates for children born in different periods were consistent at about 73%. The birth records for 1993 were not available from Vital Records. The 1992 records were still in a preliminary stage but sufficiently complete for this purpose.

APPENDIX 3

Identifying Infants at Risk

Background

In June 1994, the Birth Certificate Risk Factor Workgroup, coordinated by the Office of Children with Special Health Care Needs of the Washington Department of Health, requested assistance developing a system for assigning immunization intervention priorities based on birth certificate risk factors. The First Steps Database which links infant health outcomes to birth certificate risk factors was used in developing this system. These risk factors provide the basis for a risk scoring system which identifies the level of intervention needed when a child misses an immunization. Initially, it will be used for children in King and Snohomish counties, the CHILD Profile project site.

In response to this need and the goals of the Birth to Three Services Study, staff of the First Steps Database used the long term outcomes linked to birth certificates in the First Steps Database to develop a statistical model to identify infants at risk of adverse outcomes.

Introduction

The First Steps Database makes it possible to determine the feasibility of developing and using statistical models to predict infant risk outcomes from data available at the infant's birth. Statistically based models can be used to screen infant records and identify infants at high risk who should be monitored more closely. Two factors were considered in the development of these models: availability of data at birth and usefulness of the data in predicting risk outcomes. Given these considerations, birth certificate information was used to develop models predictive of adverse infant outcomes. Two models were developed: the first used only birth certificate data and the second combined data from birth certificates with data from the First Steps Database. Four outcomes were used as indicators of risk: infant death within the first 27 days of life (Neonatal), infant death after 27 days but within the first year of life (Postneonatal), enrollment in the Birth to Three Early Intervention programs for children with disabilities and special health care needs, and Child Protective Services (CPS) referral. These four adverse outcomes were selected because they were readily available in the First Steps Database. While they differ in severity and ascertainment[1], they represent a range of outcomes which appropriate interventions may prevent or ameliorate. For these reasons the Birth Certificate Risk Factor Work Group decided to include all four outcomes to develop a model with broad applicability.

[1] Reporting for infant deaths is quite complete; enrollment in the Birth to Three Early Intervention program is voluntary; and reporting of child abuse and neglect generally depends on community based referrals which may be subject to a variety of biases and differing community standards.

Methods

The two models were developed using SAS Logistic regression procedures. A profile was produced for each infant using a combination of mother's and infant's information. This profile was compared to outcome data, for instance, whether or not the infant died during the postneonatal period. The profiles for infants who suffered postneonatal deaths were compared to those who did not. Logistic regression was used to estimate the increase in likelihood of risk associated with each variable considered. Birth certificate information used included: birthweight, number of prenatal care visits, month prenatal care began, infant's gender, maternal smoking, Apgar score at 5 minutes (Apgar5), gestational age, number of previous children, and mother's age. In addition, the First Steps Database provided information on maternal substance abuse and Medicaid eligibility. Information on Medicaid eligibility was not available from birth certificate information for births in 1991. In 1992, however, data on the funding source for prenatal care was added to the birth certificate. It is, therefore, possible to include Medicaid status as a risk factor from birth certificate data for births that occurred after 1991.

High parity was the only combination variable used and is based upon mother's age in relation to the number of previous children she had. The infants of high parity mothers were more than 3 times as likely to become enrolled in Birth to Three services but were only 75 percent as likely to suffer neonatal death. The following conditions were used to assign status:

1) Any mother under 17 years old or more than 35 years old,
2) Age 17 to 19 with at least one previous child,
3) Age 20 to 24 with at least three previous children,
4) Age 25 to 29 with at least four previous children,
5) Age 30 to 34 with either no previous children or at least five previous children.

Two other variables were examined as predictors of infant risk. Month prenatal care began and previous live births now dead were selected for consideration after a literature review revealed that they had been included in a number of previous studies, among them Ramey, et al., 1978. In this study these variables were tested for their independent contributions to the efficacy of the model. They were rejected because they did not improve the model's ability to predict risk of adverse outcome.

Infant Risk Profile

Each infant's relative risk can be estimated using his/her profile and the estimated effects on risk of each variable in the profile. Each question is answered with either a 1 for yes or a 0 for no. When a question receives a negative response, that portion of the profile is not used in the infant's risk estimate.

Explanation of Profile:

LBW	=	Is the infant low birthweight?	1 or 0
PNC	=	Less than 12 prenatal care visits?	1 or 0
MAL	=	Is the infant male?	1 or 0
SMK	=	Did the mother smoke during pregnancy.	1 or 0
SUB	=	Did the mother abuse drugs or alcohol during pregnancy?	1 or 0
APG	=	Was Apgar score less than 8?	1 or 0
MAR	=	Is the mother unmarried?	1 or 0
MIN	=	Is the mother either African American or Native American?	1 or 0
GES	=	Was gestational age less than 37 weeks?	1 or 0
GRA	=	Is the mother a Grant Recipient?	1 or 0
EXP	=	Is the mother in the First Steps Expansion Group?	1 or 0
MED	=	Is the mother in the Medicaid Only Group?	1 or 0
HIP	=	Is the mother of high parity status?	1 or 0

Risk Estimation Formula for Any Adverse Outcome

Odds Ratio = $R = e^{P}$,

Where P = -4.361 + 0.695 LBW + 0.199 PNC + 0.151 MAL + 0.676 SMK + 1.003 APG + 0.482 MAR + 0.511 MIN + 0.304 GES + 1.132 MED + 0.263 HIP,

Probability = $\frac{R}{1+R}$

Given this set of formulas, we are able to estimate the probability that an infant will encounter at least one adverse outcome, that is, any combination of the four risks specified: Neonatal death, Postneonatal death, Birth to Three Early Intervention enrollment or CPS referral. We start by estimating the odds ratio for an infant; the odds ratio indicates the infant's odds of adverse outcome relative to infants with none of the characteristics we have associated with adverse outcome. The odds ratio is used to estimate an infant's probability of adverse outcome; probabilities vary from 0 to 100 percent. While none of the infants had a 100 percent probability of adverse outcome, there was a great difference between the highest and lowest probabilities, from 74.4% to 1.3%. This distribution of probabilities is a useful tool which identifies the infants at greatest risk of adverse outcome.

Findings

The factors used in these risk models varied greatly in their effect on risk estimates. Several, however, had strong and consistent effects on infant risk estimates. Infants who received Apgar5 scores of less than 8 had elevated risk levels in 4 of the 5 risk outcomes: the most pronounced was an odds ratio of 24 for neonatal death, meaning these infants were 24 times as likely to suffer neonatal death as infants who scored 8 or more. They also had an odds ratio of over 4 for postneonatal death. Low birthweight infants (infants with birthweight less than 2500 grams) were found to be at increased risk for four risk outcomes; they were more than 6 times as likely to suffer Neonatal Death and more than twice as likely to become enrolled in Birth to Three services.

Sensitivity and Specificity

Given the complexity of predicting infant risk and the lack of total and perfect data, we are unable to achieve perfect prediction with our model. We are, however, able to estimate the accuracy of our model with two measures: sensitivity and specificity. Sensitivity compares the number of correctly predicted positive outcomes to the total number of positive outcomes. Specificity compares the number of correctly predicted negative outcomes to the total number of negative outcomes.

figure 1

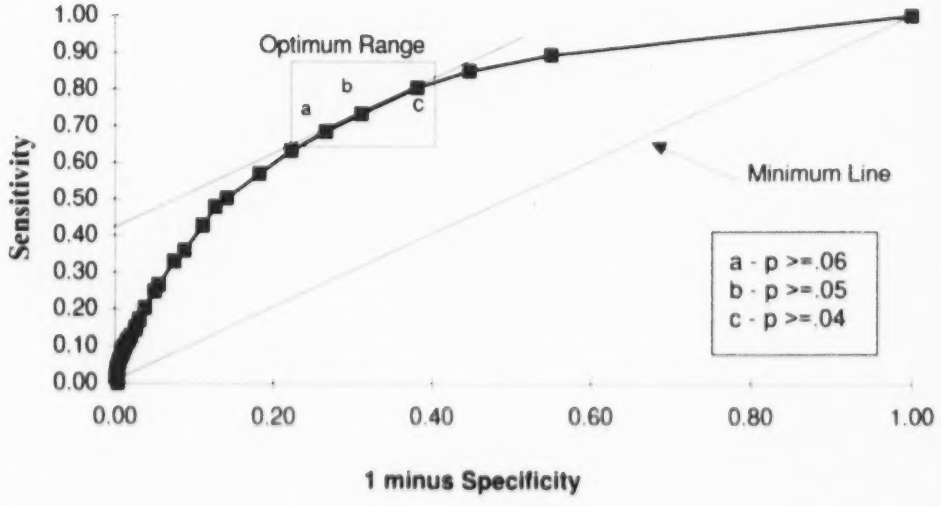
		outcome					
		yes	no				
prediction	yes	1536	11937	13473	Sensitivity	Se	0.73
	no	564	26405	26969	Specificity	Sp	0.69
		2100	38342	40442			

In this case, we have correctly predicted a positive outcome for 1536 cases and incorrectly predicted negative outcomes for 564 cases. Comparing the two we find that we correctly predicted positive outcomes for 1,536 of 2,100 cases, a sensitivity of 0.73. We correctly predicted negative outcomes in 26,405 of 38,342 cases, for a specificity of 0.69.

We can now estimate the accuracy of our model with sensitivity and specificity. We can use adverse outcome probability as our criterion for selection. By changing criterion level we change sensitivity, specificity and the number of infants monitored. It would be useful to evaluate specificity and sensitivity with respect to the number of infants monitored. We can find the optimum combination of sensitivity and specificity using the graphical method depicted in figure 2. Points a,b and c are in the optimum range, determined by finding the points on the curved line which maximize sensitivity with respect to specificity. In a graphical sense this is the area on the curved line farthest from the minimum line. We find that the optimum combination of sensitivity and specificity is achieved when we set the cutoff probability at 0.05. Any infant with a risk probability of at least 0.05 will be monitored. We can generalize these results to any other group of infants as long as there are not considerable differences between the groups.

figure 2

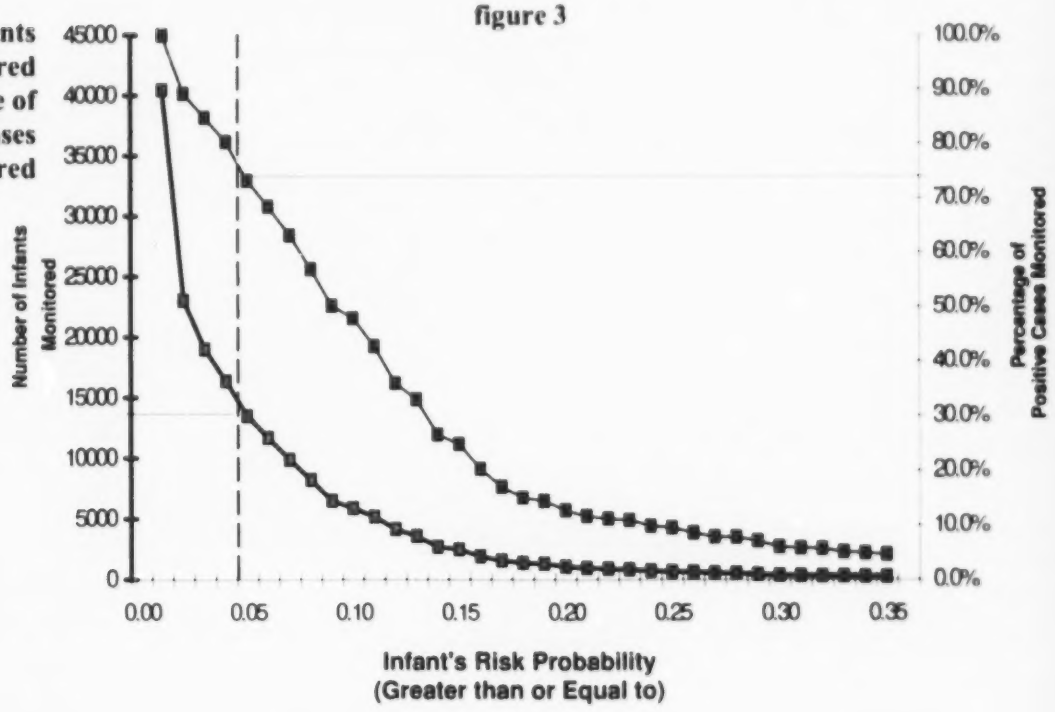
Sensitivity versus Specificity



Using figure 3 we find that there are about 13,500 infants with adverse outcome probabilities of at least 0.05, this means we will not monitor about 26,500 infants whose risks of adverse outcome were less than 0.05. By monitoring 13,500 infants, or 33 percent of the infants in this group, we will capture about 67 percent of the infants who will encounter at least one of the designated adverse outcomes: 1) Neonatal death, 2) Post neonatal death, 3) Birth to Three Early Intervention enrollment or 4) CPS referral. In order to identify 100 percent of the infants who will have adverse outcomes we will have to monitor all infants born.

figure 3

Number of Infants Monitored and Percentage of Positive Cases Monitored



Summary

Maternal prenatal characteristics and infant characteristics at birth can influence an infant's probability of encountering an adverse outcome later in life. By using information from birth certificates as well as Medicaid information for 40,442 infants, all infants born in Washington State between July and December 1991, a risk model was developed to identify infants at greatest risk of encountering any of four specified adverse outcomes: Neonatal death, Postneonatal death, Birth to Three Early Intervention enrollment or CPS referral.

Ten characteristics were identified as having an association with risk of adverse outcome: Inadequate Prenatal Care, Smoking during Pregnancy, Mother's Marital Status, Mother's Race/Ethnicity, Mother's Medicaid Eligibility, Mother's Age compared to the number of previous children, Infant's Birthweight, Infant's Gender, Infant's Apgar score at 5 minutes, and Infant's Gestational Age. Risk associations were estimated for each characteristic using a statistical method known as logistic regression. By considering risk associations for all specified characteristics in sum it was possible to estimate each infant's overall probability of encountering one of the specified adverse outcomes.

While none of the infants had a 100% probability of adverse outcome, there was a considerable distribution of probabilities, from 1.3% to 77.4%. Efforts to monitor infants at risk should start with those infants with the highest risk of adverse outcome. This strategy will improve the results of efforts to reach infants at risk. Using three risk levels will allow service providers to target assistance where it is most needed, children at greatest risk of adverse outcome. It was decided that the highest priority, priority one, would be assigned to infants with a risk probability of at least 0.15. These infants make up 6 percent of infants and have an average risk of 0.24, or about 1 in 4. Priority two will be assigned to infants with a risk probability of at least 0.05 but less than 0.15. These infants make up 27 percent of infants and have an average risk of 0.08, or about 1 in 12. Priority three will be assigned to infants with a risk probability of less than 0.05. These infants make up 67 percent of infants and have an average risk of 0.02, or about 1 in 50.

Table 1

	Statewide Number of Births Jun - Dec 1991 (%)	Range of Risk Probability	Average Risk Probability
Priority One	2466 (6%)	> 0.15 (> 3/20)	0.24 (1/4)
Priority Two	11007 (27%)	0.05 - 0.15 (1/20 - 3/20)	0.08 (1/12)
Priority Three	26969 (67%)	< 0.05 (< 1/20)	0.02 (1/50)

Table 2

Risk Factor Odds Ratios for Infant Adverse Outcomes Using Only Birth Certificate Data

Risk Factors	N	CPS	Birth to 3	Neonatal Death	Post Neonatal Death	Any Adverse Outcome
Low Birthweight	2352	1.30 *	2.70 *	6.29 *	0.95	2.00 *
Less than 12 PNC visits	20024	1.37 *	0.89	1.95 *	0.93	1.23 *
Infant is male	20692	1.06	1.50 *	0.80	1.05	1.16 *
Prenatal Smoking	7073	2.44 *	1.20	1.24	1.37	1.97 *
Low Apgar Score	1608	1.08	2.50 *	24.10 *	4.50 *	2.73 *
Mother Unmarried	10303	2.18 *	0.98	0.93	1.47	1.62 *
Minority [1]	2332	2.05 *	1.10	1.28	0.92	1.67 *
Gestational age less than 37 weeks	3800	1.10	1.44 *	1.75 *	1.47	1.36 *
Medicaid [2]	15240	4.59 *	2.49 *	1.06	1.39	3.10 *
High Parity	5863	1.39 *	1.23 *	0.74	1.85 *	1.30 *

Table 3

Risk Factor Odds Ratios for Infant Adverse Outcomes Using Birth Certificate and First Steps Data

Risk Factors	N	CPS	Birth to 3	Neonatal Death	Post Neonatal Death	Any Adverse Outcome
Low Birthweight	2352	1.22	2.65 *	6.26 *	0.93	1.97 *
Less than 12 PNC visits	20024	1.34 *	0.88	1.95 *	0.94	1.22 *
Infant is male	20692	1.06	1.50 *	0.80	1.05	1.17 *
Prenatal Smoking	7073	2.00 *	1.11	1.32	1.19	1.68 *
Prenatal Substance Abuse	943	4.65 *	2.03 *	1.06	2.75 *	3.88 *
Low Apgar Score	1608	1.02	2.47 *	24.06 *	4.42 *	2.75 *
Mother Unmarried	10303	1.71 *	0.90	1.02	1.23	1.34 *
Minority [1]	2332	1.54 *	0.99	1.36	0.73	1.33 *
Gestational age less than 37 weeks	3800	1.06	1.44 *	1.76 *	1.46	1.34 *
Grant Recipient	7592	5.60 *	2.64 *	0.72	1.76	3.70 *
FS Expansion Group	4426	2.38 *	2.16 *	1.29	0.82	2.01 *
Medicaid Only	3222	3.94 *	2.43 *	1.41	1.15	2.66 *
High Parity	5863	1.39 *	1.23 *	0.73	1.84 *	1.29 *

* Significant at $p < .05$

1 Minority status was defined as African American or Native American.

2 This study used birth certificates for 1991 and they do not include information on Medicaid status at time of birth. Payee information is available from 1992 birth certificates.

Appendix 4

Ascertainment Rates of Major Birth Defects for Washington Born Medicaid Infants Compared to National and Regional Rates for All Children

	Medicaid Total	Medicaid* Rate per 1000	CDC Rates** U.S.	Western U.S.
Down's Syndrome	55	0.91	0.97	1.17
Cleft Lip/Palate	81	1.34	1.49	1.42
Spina Bifida	32	0.53	0.45	0.45

* Total Medicaid = 60312

** Centers for Disease Control: Congenital Malformations Surveillance Report January 1982 - December 1985, Issued March 1988.

- The ascertainment rates of major birth defects (Down's Syndrome, Cleft Lip/Palate, Spina Bifida) among Washington born Medicaid infants is very similar to the national and regional rates for all children as reported by the Centers for Disease Control and Prevention.

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